Webinar Series: Health Care Transition & Title V Care Coordination Initiatives

A five-part Webinar Series featuring examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies.

Session 2 · Transition Preparation

- Identifying key components of HCT policy for CC programs that families/youth want to know
- Customizing transition readiness assessment (RA) for CC programs
- Piloting and disseminating HCT policy and RA
- Incorporating RA skill needs into plan of care and educating youth and families on needed skills
- Preparing medical summary and emergency care plan with youth and families and their providers

Click here to view webinar recording on YouTube

MATERIALS INCLUDE:
- Care Coordination Webinar 2 Slides: Transition Preparation
- HCT Readiness Assessment for Youth & Caregivers
- Medical Summary for YAs with ID/DD
- HCT Readiness Assessment for YAs & Caregivers of YAs with ID/DD
- "Medical ID" Feature/App for Apple and Android phones
- DC Transition Materials – Michelle Jiggetts

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Health Care Transition & Title V Care Coordination Initiatives: Webinar Series

Webinar # 2 | March 28, 2018

TRANSITION PREPARATION

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Program Administrator
Complex Care Program and Parent Navigator Program
Children's National Health System’s Goldberg Center

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Co-Director, Got Transition
The National Alliance to Advance Adolescent Health
Michelle Jiggetts and Patience White have no financial disclosures or conflicts of interest.

Got Transition, a program of The National Alliance to Advance Adolescent Health, is funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, DHHS.
Got Transition’s Webinar Series Goals

• Support state Title V implementation and measurement of health care transition (HCT) in care coordination programs
• Guide care coordination improvements by sequentially building on the evidence-informed Six Core Elements
• Share promising practices from state Title V-supported care coordination programs (CC)
• 5-session webinar series on HCT and care coordination
• The webinars and handouts will be available following each session at www.gottransition.org
Webinar #2 Objectives

At the conclusion of Webinar 2, attendees will be able to...

- Identify key components of HCT policy for CC programs that families/youth want to know
- Customize transition readiness assessment (RA) for CC programs
- Pilot and disseminate HCT policy and RA
- Incorporate RA skill needs into plan of care and educate youth and families on needed skills
- Prepare medical summary and emergency care plan with youth and families and their providers
Webinar #2 Handouts

1. Webinar #2 Slideshow
2. iPhone and Android Info sheets
3. Got Transition RA
4. Youth with ID/DD and parent readiness assessments
5. Medical Summary for youth with ID/DD
Webinar #1 REVIEW

- HCT Clinical Foundations
- HCT Performance Measurement
- Title V Baseline Assessment
- Starting a HCT Pilot using Quality Improvement and the Core Element Processes
HCT Clinical Foundations

Six Core Elements of HCT:
Transitioning Youth to an Adult Clinician

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer/Integration into Adult-Centered Care
6. Transition Completion/Ongoing Care
Sample Forms and Templates

- Discuss transition policy
- Track progress
- Assess skills
- Develop transition plan
- Transfer documents
- Confirm completion

AGE 12-14
AGE 14-15-16-17-18
AGE 14-15-16-17-18
AGE 14-15-16-17-18
AGE 18-21
3-6 months after transfer

Sample Forms and Templates
TRANSITION POLICY
Core Element #1: POLICY

**Purpose:** Formalize CC program’s approach, reduce care coordinators’ variability and offer a transparent approach to youth and families

**Content:**
- Define program approach and recommended ages for transition preparation for adult-focused care, transfer, and integration into adult care
- Clarify adult approach to care and legal changes at age 18
- Reading level should be appropriate

**Post:** Communicate it to all involved early in the process
Transition Policy Challenges

- How to establish a written HCT policy?
- What topics should be included in a policy?
- How best to get youth and family/caregiver involvement and feedback?
- How and with whom should the policy be shared?
Core Element #2: TRANSITION TRACKING & MONITORING

**Purpose:** Facilitate systematic data collection to improve quality at individual and population levels

**Content:**
- Demographic and diagnostic/complexity data
- Date of receipt of each core element (e.g., policy shared, readiness assessment administered, etc.)

**Format:** paper checklist, excel spreadsheet, EHR
Transition Tracking & Monitoring Challenges

• What information should be tracked – e.g., name, date of birth, case mix complexity, diagnosis, date of receipt of each core element?

• What options are available to track and trigger use of core elements within CC programs?
TRANSITION READINESS
“First they make you button your own shirt, then they make you tie your own shoes...you gotta ask yourself — where’s this all heading?”
Core Element #3: TRANSITION READINESS

**Purpose:** Assess the youth’s skills to manage their health/health care in the adult approach to care.

**Content:**
- Ranks importance of changing to adult provider before age 22
- Ranks confidence about ability of changing to adult provider
- Assesses self-care skills related to own health and using health care services

**Use:**
- Completed several times during the transition process
- Used as a discussion tool to plan skill-building education
- Does not predict transition success
- Customized to meet the needs of the practice’s population
Assessment indicators of importance and confidence added to the readiness assessment tool (post testing)

- Drawn from decision making & motivational interviewing content
- Includes questions with rating scale:

1. **Importance**: How do you feel at this moment about Moving to a doctor who cares for adults? How important is it to you personally to manage your own health care? (If 0 was not important and 10 was very important, what number would you give yourself?)

2. **Confidence**: If you decided right now to transfer to an adult provider, how confident do you feel about succeeding with this? (If 0 is not confident and 10 is very confident, what number would you give yourself?)

**Clinician action**: If importance rating is low, focus on this first; if ratings are roughly equal, start with importance
Strategies for Youth Uptake of Key Health Information Knowledge

Smart Phone

- Majority of youth/young adults have a cell phone
- Add health information to their phone e.g. diagnosis, allergies, medications, who to contact in an emergency
- Accessible without a passcode for access (EMS, others)
- Facilitates their ability to communicate/keep track of key health information
- Example: Health Apps for iPhones
ACP Council on Subspecialties Transition Initiative

- Partnership with Got Transition in 2016
- Customized Six Core Elements' transition readiness assessment, self-care assessment, and medical summary for selected conditions (teams included representatives from pediatric and adult professional and patient groups):
  - General Medicine (SGIM, SAHM, HCTN, ACP, AAP, AAFP, AOA, Med-Ped Program Directors)
  - ID/DD
  - Physical disabilities
  - Hematology (Hemophilia, Sickle Cell Disease), Cardiology (CHD), Endocrine Society (Diabetes), Gastroenterology (IBD), Neurology (Epilepsy), Nephrology (ESRD), Rheumatology (JIA, SLE)
- Available at www.gottransition.org under News and Announcements or ACP website www.acponline.org
Pediatric to Adult Care Transitions Tools  

Transition Readiness Assessment for Youth with Intellectual/Developmental Disabilities

This document should be completed by youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their readiness to transition to an adult health care provider. If a youth’s intellectual or developmental disabilities prevent him or her from independently filling out this document, the youth’s caregiver should fill out the caregiver version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what you already know about your health and using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

<table>
<thead>
<tr>
<th>Date:</th>
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<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Birth:</th>
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</table>

**Legal Choices for Making Health Care Decisions**
- [ ] I can make my own health care choices.
- [ ] I need some help with making health care choices (Name: ____________ Consent: ____________).
- [ ] I have a legal guardian (Name: ____________).
- [ ] I need a referral to community services for legal help with health care decisions and guardianship.

**Personal Care**
- [ ] I care for my all my needs.
- [ ] I care for my own needs with help.
- [ ] I am unable to provide self-care, but can direct others.
- [ ] I require total personal care assistance.

**Transition and Self-Care Importance and Confidence**  
On a scale of 0 to 10, please circle the number that best describes how you feel right now.

<table>
<thead>
<tr>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
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<tbody>
<tr>
<td>How important is it to you to take care of your own health care and change to adult doctor before age 22?</td>
<td></td>
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<tr>
<td>How confident do you feel about your ability to take care of your own health care and change to an adult doctor before age 22?</td>
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**My Health**

Please check the box that applies to you right now. 

<table>
<thead>
<tr>
<th>Yes, I know this</th>
<th>I need to learn</th>
<th>Someone needs to do this</th>
<th>Who?</th>
</tr>
</thead>
</table>
Transition Readiness Challenges

• What skills about health and health care are important for CC clients to know?
• How can youth and family/caregiver involvement and feedback on the RA be obtained?
• When should transition readiness be assessed?
• Will youth and parents complete the RA on their own or will the CC administer the RA?
Core Element #4: TRANSITION PLANNING

**Purpose:** Establish agreement between youth and CC and/or clinician about set of actions to address priorities and access current medical information

**Content:**

- Identify what matters most to youth in becoming adult beyond health goals
- Define how learning about health and health care supports youth’s over all goals (add readiness assessment skill needs to the plan)
- ACP project developed POC templates for ID, physical disabilities along with some subspecialty diseases (see www.gottransition.org)

Also complete portable medical summary and emergency care plan with “special information” non medical for adult provider
This document should be completed by medical providers, in collaboration with youth and their caregivers. A copy of this completed document should be shared with and carried by youth and caregivers to facilitate comprehensive information transfer and chart review when establishing care with new medical providers.

Date Completed: Date Revised:

**Contact Information**

- **Name:**
- **DOB:** Preferred Language:
- **Address:**
- **Cell #:** Home #: Best Time to Reach:
- **E-Mail:**
- **Parent/Caregiver:** Relationship:
- **Address:**
- **Cell #:** Home #: Best Time to Reach:
- **E-Mail:**
- **Health Insurance/Plan:**

Please add special information about strengths that the youth/caregiver wants their new health care team to know:

**Developmental Disability**

- Nervous System:
  - Attention spectrum disorder
  - Down syndrome
  - Fetal Alcohol Syndrome
  - Fragile X
  - Intellectual disability
  - Rett syndrome
  - Spina bifida
  - Tourette syndrome
  - Other (Specify):

- Sensory System:
  - Visual
  - Auditory
  - Gustatory
  - Olfactory
  - Tactile
  - Proprioceptive
  - Vestibular
  - Other (Specify):

- Motor System:
  - Muscular dystrophy
  - Other (Specify):

- Other:
  - Adhd
  - Hearing impairment
  - Visual impairment
  - Seizures
  - Cardiac Condition
  - Obesity
  - OSA
  - Other (Specify):

**Adaptive Functioning Domains**

- Communication:
- Self-Distraction:
- Community Activities:
- Work:
- Functional Academics:
  - Functional Grade Level:
  - Date Tested:
  - Iq:
  - Date Tested:

**Emergency Care Plan**

- Emergency Contact:
- Relationship:
- Phone:

**Allergies and Procedures to be Avoided**

<table>
<thead>
<tr>
<th>Allergies</th>
<th>Reactions</th>
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<tbody>
<tr>
<td>To be avoided</td>
<td>Why?</td>
</tr>
<tr>
<td>Medical Procedures:</td>
<td></td>
</tr>
</tbody>
</table>

**Diseases and Current Problems**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Details and Recommendations</th>
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<tbody>
<tr>
<td>Primary Diagnosis</td>
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<tr>
<td>Secondary Diagnosis</td>
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<tr>
<td>Behavioral</td>
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<tr>
<td>Communication</td>
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<tr>
<td>Food &amp; Swallowing</td>
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<tr>
<td>Hearing/Vision</td>
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<tr>
<td>Learning</td>
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<tr>
<td>Orthopedic/Neurological</td>
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<tr>
<td>Physical Anomalies</td>
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<tr>
<td>Respiratory</td>
<td></td>
</tr>
<tr>
<td>Sensory</td>
<td></td>
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</tbody>
</table>
Transition Planning Challenges

- How to incorporate HCT into plan of care?
- How can youth and family/caregiver involvement and feedback on HCT plan of Care be obtained?
- How can CC programs enable HCP to complete medical summary and emergency care plan?
- Who will provide needed self care education?
What to do? Where to start?
Introductory Remarks

Djinge Lindsay, MD, MPH
Deputy Director for Policy and Programs
Community Health Administration (CHA)
Parent Navigators:
Making the Transition Connection in DC

Got Transition Webinar
Health Care Transition & Title V Care Coordination
“Transition Planning”

Michelle Jiggetts, MD, MS, MBA
March 28, 2018
Objectives

• Discuss History of Parent Navigator Program
• Discuss role of Parent Navigators
• Discuss Transition integration into the Medical Home setting using the Six Core Elements
• Next Steps
Parent Navigator Program: Our Story

• Program established in 2008
• Based in Goldberg Center for Community Pediatric Health
  – Children’s National COE
  – Support from DC DOH and Maryland DHMH
• Composed of parents of children with special health care needs (CSHCN) employed by the hospital to provide peer support to other families of CSHCN
  – Currently have 6 full time PN’s
  – Available to families of CYSHCN receiving primary care and complex care services at Children’s National
Parent Navigator: A Key Member of the Medical Healthcare Team

- Primary Care Medical Home
- School Nurse
- Specialty Physicians
- Parent Navigator
- Inpatient Care Team
- Private Duty Nurse
- Community Therapists
- Insurance Case Manager
Roles and Responsibilities

Based on Pediatricians and Family Needs
• Provide Peer-to-Peer support
• Coach families how to advocate for their child
• Help families to communicate more effectively with health care professionals
• Coach families how to navigate services throughout the hospital and in the community
• Link families to community and educational resources
• Work with families to understand their educational rights and responsibilities (e.g. IFSP, IEP, 504)
• Provide follow-up with families to ensure needs are met
• Prepare families for transitioning to adult health services
Integrating Transition

• Formulated a Transition team
  – Program Administrator, Navigators, Physicians from both primary and adolescent departments
• Facilitate bi-weekly transition meetings
• Reviewed Six Core Element toolkit
• Performed a Self-Evaluation
• Designed Transition Integration according to the Six Core Elements
Self Evaluation

• Reviewed ‘Got Transition’ National Standards
Putting the Six Core Element Pieces Together

- Transition Policy
- Transition Tracking & Monitoring
- Transition Readiness
- Transition Planning
- Transfer of Care
- Transfer Completion
Transition Policy

**Six Core Element National Standard**

- Develop a transition policy/statement with input from youth and families that describe the practice’s approach to transition, including privacy and consent information.
- Educate all staff about the practice’s approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
- Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

**Navigator’s Role**

- A Transition policy/statement has been developed, uploaded to our intranet.
- Educated management staff and Adolescent providers on the particulars of the policy.
- Policy is discussed with youth and families, beginning at age 14 when the Readiness Assessment is completed.
Transition Tracking & Monitoring

**Six Core Element National Standard**

- Establish criteria and process for identifying transitioning youth and enter their data into a registry.
- Utilize individual flow sheet or registry to track youth’s transition progress with the *Six Core Elements*.
- Incorporate the *Six Core Elements* into clinical care process, using HER if possible

**Navigator’s Role**

- Established criteria and process for identifying transitioning youth and enter their data into a registry.
  - All children between 14-21 years with complex medical needs, autism and developmental delay
  - Receive a list every week of eligible teens that have upcoming appointments
  - List is divided up among navigators according to alphabet
- Created a registry to track youth’s transition planning
PN Transition Registry

Excel Registry

Components of the Transition Registry

- Name
- Patient Residence
- Service location
- Insurance
- Attempts Made ($1^{st}$, $2^{nd}$, $3^{rd}$)
- Date RA Obtained
- Goals Discussed
- Adult Provider Name
- Date of Appt.
- Feedback
Transition Readiness

Six Core Element National Standard

- Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
- Jointly develop goals and prioritized actions with youth and parent/caregiver and document regularly in a plan of care.

Navigator’s Role

- Conduct regular transition readiness assessments, beginning at age 14-21
  - Verification of cognitive level and age of patient to determine if the child or the parent should complete the Readiness Assessment (RA)
- Generate weekly calls to families
- Meet family at the visit
- Discuss goals and prioritize actions with youth and parent/caregiver.
- Utilize registry to track youth’s transition
  - RA documented in EMR
  - Telephone Encounter sent to provider seeing pt. to notify them of Administer the RA
Documentation of RA
## Goals Discussed

<table>
<thead>
<tr>
<th>Date</th>
<th>RA Obtained</th>
<th>RA Admin Date</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/3/2017</td>
<td>Yes</td>
<td>2/3/2017</td>
<td>Mother obtaining Guardianship</td>
</tr>
<tr>
<td>5/14/2017</td>
<td>YES</td>
<td>5/14/2017</td>
<td>Foster care - no goals</td>
</tr>
<tr>
<td>4/14/2017</td>
<td>YES</td>
<td>4/14/2017</td>
<td>Discussed Guardianship &amp; other decision making options</td>
</tr>
<tr>
<td>5/11/2016</td>
<td>YES</td>
<td>5/11/2016</td>
<td>Know where to get medical care when doctor's office is closed</td>
</tr>
<tr>
<td></td>
<td>YES</td>
<td>12/28/2016</td>
<td>Mother obtaining Guardianship</td>
</tr>
<tr>
<td>12/15/2016</td>
<td>YES</td>
<td>12/15/2016</td>
<td>Mom plans on Power of Attorney. Plans on working with daughter on knowing when and how to call 911</td>
</tr>
<tr>
<td>NO</td>
<td></td>
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</table>
Transition Planning

Six Core Element National Standard

- Including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and if needed, a condition fact sheet and legal documents.
- Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy and access to information.
- Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
- Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.
- Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.
- Provide linkages to insurance resources, self-care management information and culturally appropriate community supports.

Navigator’s Role

- Prepare youth and parent/caregiver for adult approach to care at age 18. Start the discussion around Power of Attorney versus Guardianship.
- Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
- Dissemination of guardian decision making and guardianship brochure.
- Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.
  - PN provides family an adult provider list.
- Provide linkages to insurance resources, self-care management information and culturally appropriate community resources.
Transfer of Care

**Six Core Element National Standard**

- Confirm date of first adult provider appointment.
- Transfer young adults when his/her condition is stable.
- Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and it needed, legal documents, condition fact sheet, and additional provider records.
- Prepare letter with transfer package, send to adult practice and confirm adult practice’s receipt of transfer package.
- Confirm with adult provider the pediatric provider’s responsibility for care until young adult is seen in adult setting.

**Navigator’s Role**

- Navigator assists family with scheduling the initial adult primary care visit.
- Assists family with getting a copy of the medical visit summary and an immunization record.
Transfer Completion

**Six Core Element National Standard**

- Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process.
- Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.
- Build ongoing and collaborative partnerships with adult primary and specialty care providers.

**Navigator’s Role**

- Navigators contacts families approximately 2 wks. after the appt. to verify attendance.
Reasons for continuing to do this...
Parent Comments

• “I never really thought about guardianship, happy that you’re doing it.”

• “Don’t know what my child is able to do. I can start working on goals with her.”

• “Wish I started this process earlier.”

• “Why are you starting at 14 years of age.”
Next Steps

- Develop Training workshops for families
- Develop Training workshops for providers
- Collaborate with hospital staff to strategize on making this a hospital-wide effort
Questions?

• About writing HCT Policy with staff, youth and family and sharing it with them?

• About customizing the RA?

• About creating a plan of care with HCT components such as with RA skill needs?

• About how DC’s Parent Navigator Program implements the 6 Core Element Process?
Upcoming Title V Care Coordination Webinars

Transfer to Adult Care
April 26, 3-4 pm ET

Integration into Adult Care
May 31, 3-4 pm ET

Youth, Young Adult, & Parent Engagement
June 28, 3-4 pm ET

To register, please visit Got Transition's website under Webinars (www.gottransition.org/webinars)
Thank You!

WEBSITE
www.gottransition.org
See link to new transition news and articles and download the Six Core Elements 2.0 packages to start making HCT quality improvements in your practice

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mjiggett@childrensnational.org
pwhite@thenationalalliance.org

FACEBOOK PAGE
HealthCareTransition

TWITTER
@gottransition2
### Pediatric to Adult Care Transitions Tools

**Medical Summary & Emergency Care Plan for Young Adults with Intellectual/Developmental Disabilities**

This document should be completed by medical providers, in collaboration with youth and their caregivers. A copy of this completed document should be shared with and carried by youth and caregivers to facilitate comprehensive information transfer and chart review when establishing care with new medical providers.

<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
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**Contact Information**

- **Name:**
- **Nickname:**
- **DOB:**
- **Preferred Language:**
- **Address:**
- **Cell #:**
- **Home #:**
- **E-Mail:**
- **Best Time to Reach:**
- **Best Way to Reach:** Text, Phone, Email
- **Parent (Caregiver):**
- **Relationship:**
- **Address:**
- **Cell #:**
- **Home #:**
- **E-Mail:**
- **Best Time to Reach:**
- **Best Way to Reach:** Text, Phone, Email
- **Health Insurance/Plan:**
- **Group and ID #:**

Please add special information about strengths that the youth/caregiver wants their new health care team to know:

---

### Developmental Disability

#### Sensory System:

- Visual
- Auditory
- Gustatory
- Olfactory
- Tactile
- Proprioceptive
- Vestibular
- Other (Specify):

#### Motor System:

- Cerebral palsy
- Down syndrome
- Fetal Alcohol Syndrome
- Fragile X
- Intellectual disability
- Rett syndrome
- Spina bifida
- Tourette syndrome
- Other (Specify):

#### Other:

- ADHD
- Hearing impairment
- Visual impairment
- Seizures
- Cardiac Condition
- Obesity
- OSA
- Other (Specify):

#### Degenerative:

- Muscular dystrophy
- Other (Specify):

#### Co-occurring Psychological Issues:

- Depression
- Aggression
- Anxiety
- Relational
- Self-injurious Behavior
- Other (Specify):

#### Metabolism:

- Congenital hypothyroidism
- Phenylketonuria
- Other (Specify):

#### Etiology:

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# Pediatric to Adult Care Transitions Tools

## Medical Summary & Emergency Care Plan for Young Adults with Intellectual/Developmental Disabilities

### Adaptive Functioning Domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Functioning</th>
<th>Communication</th>
<th>Social</th>
<th>Self Direction</th>
<th>Community Activities</th>
<th>Work</th>
<th>Functional Academics</th>
<th>Functional Grade Level</th>
<th>Date Tested</th>
<th>FSIQ</th>
<th>Date Tested</th>
<th>Home Living</th>
<th>Leisure</th>
<th>Sleep Issues</th>
<th>Nutritional Issues</th>
<th>Quality of Life Issues</th>
<th>Safety Issues</th>
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### Emergency Care Plan

<table>
<thead>
<tr>
<th>Emergency Contact</th>
<th>Relationship</th>
<th>Phone</th>
<th>Preferred Emergency Care Location</th>
<th>Common Emergency Presenting Problems</th>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
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### Special Concerns for Disaster:

#### Allergies and Procedures to be Avoided

<table>
<thead>
<tr>
<th>Allergies</th>
<th>Reactions</th>
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#### Diagnoses and Current Problems

<table>
<thead>
<tr>
<th>Problem</th>
<th>Details and Recommendations</th>
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<tbody>
<tr>
<td>Primary Diagnosis</td>
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<tr>
<td>Secondary Diagnosis</td>
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<td>Behavioral</td>
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<td>Communication</td>
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<td>Food &amp; Swallowing</td>
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<td>Hearing/Vision</td>
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<tr>
<td>Learning</td>
<td></td>
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<tr>
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<td>Physical Anomalies</td>
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<tr>
<td>Respiratory</td>
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</tr>
<tr>
<td>Sensory</td>
<td></td>
</tr>
<tr>
<td>Stamina/Fatigue</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
Sample Transition Readiness Assessment for Youth
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date:

Name:                                                                                       Date of Birth:

Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to prepare for/change to an adult doctor before age 22?

<table>
<thead>
<tr>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
</tr>
</thead>
</table>

How confident do you feel about your ability to prepare for/change to an adult doctor?

<table>
<thead>
<tr>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
</tr>
</thead>
</table>

My Health

Please check the box that applies to you right now.

Yes, I know this | I need to learn | Someone needs to do this… Who?

I know my medical needs.                      ☐ ☐ ☐
I can explain my medical needs to others.     ☐ ☐ ☐
I know my symptoms including ones that I quickly need to see a doctor for. ☐ ☐ ☐
I know what to do in case I have a medical emergency. ☐ ☐ ☐
I know my own medicines, what they are for, and when I need to take them. ☐ ☐ ☐
I know my allergies to medicines and medicines I should not take. ☐ ☐ ☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary). ☐ ☐ ☐
I understand how health care privacy changes at age 18 when legally an adult. ☐ ☐ ☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment. ☐ ☐ ☐

Using Health Care

I know or I can find my doctor’s phone number. ☐ ☐ ☐
I make my own doctor appointments. ☐ ☐ ☐
Before a visit, I think about questions to ask. ☐ ☐ ☐
I have a way to get to my doctor’s office. ☐ ☐ ☐
I know to show up 15 minutes before the visit to check in. ☐ ☐ ☐
I know where to go to get medical care when the doctor’s office is closed. ☐ ☐ ☐
I have a file at home for my medical information. ☐ ☐ ☐
I have a copy of my current plan of care. ☐ ☐ ☐
I know how to fill out medical forms. ☐ ☐ ☐
I know how to get referrals to other providers. ☐ ☐ ☐
I know where my pharmacy is and how to refill my medicines. ☐ ☐ ☐
I know where to get blood work or x-rays if my doctor orders them. ☐ ☐ ☐
I have a plan so I can keep my health insurance after 18 or older. ☐ ☐ ☐
My family and I have discussed my ability to make my own health care decisions at age 18. ☐ ☐ ☐
Sample Transition Readiness Assessment
for Parents/Caregivers
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child’s health care skills.

Date: ___________________________  Name: ___________________________
Date of Birth: __________________

Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it for your child to prepare for/change to an adult doctor before age 22?

<table>
<thead>
<tr>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
</tr>
</thead>
</table>

How confident do you feel about your child’s ability to prepare for/change to an adult doctor?

<table>
<thead>
<tr>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
</tr>
</thead>
</table>

My Health

Please check the box that applies to your child right now.

Yes, he/she knows this  He/she needs to learn  Someone needs to do this… Who?

My child knows his/her medical needs.

My child can explain his/her medical needs to others.

My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.

My child knows what to do in case he/she has a medical emergency.

My child knows his/her own medicines, what they are for, and when he/she needs to take them.

My child knows his/her allergies to medicines and medicines he/she should not take.

My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).

My child knows he/she can see a doctor alone as I wait in the waiting room.

My child understands how health care privacy changes at age 18.

My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.

Using Health Care

My child knows or can find his/her doctor’s phone number.

My child makes his/her own doctor appointments.

Before a visit, my child thinks about questions to ask.

My child has a way to get to his/her doctor’s office.

My child knows to show up 15 minutes before the visit to check in.

My child knows where to go to get medical care when the doctor’s office is closed.

My child has a file at home for his/her medical information.

My child has a copy of his/her current plan of care.

My child knows how to fill out medical forms.

My child knows how to get referrals to other providers.

My child knows where his/her pharmacy is and how to refill his/her medicines.

My child knows where to get blood work or x-rays if his/her doctor orders them.

My child has a plan to keep his/her health insurance after ages 18 or older.

My child and I have discussed his/her ability to make his/her own health care decisions at age 18.

My child and I have discussed a plan for supported decision-making, if needed.
This document should be completed by medical providers, in collaboration with youth and their caregivers. A copy of this completed document should be shared with and carried by youth and caregivers to facilitate comprehensive information transfer and chart review when establishing care with new medical providers.

<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Form completed by:</td>
<td></td>
</tr>
</tbody>
</table>

**Contact Information**

**Name:**

**DOB:**

**Address:**

**Cell #:**

**Home #:**

**E-Mail:**

**Best Time to Reach:**

**Best Way to Reach:**

**Parent (Caregiver):**

**Address:**

**Cell #:**

**Home #:**

**E-Mail:**

**Best Time to Reach:**

**Best Way to Reach:**

**Health Insurance/Plan:**

**Group and ID #:**

Please add special information about strengths that the youth/caregiver wants their new health care team to know:

<table>
<thead>
<tr>
<th>Developmental Disability</th>
<th>Sensory System:</th>
<th>Other:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Autism spectrum disorder</td>
<td>□ Visual</td>
<td>□ ADHD</td>
</tr>
<tr>
<td>□ Cerebral palsy</td>
<td>□ Auditory</td>
<td>□ Hearing impairment</td>
</tr>
<tr>
<td>□ Down syndrome</td>
<td>□ Gustatory</td>
<td>□ Visual impairment</td>
</tr>
<tr>
<td>□ Fetal Alcohol Syndrome</td>
<td>□ Olfactory</td>
<td>□ Seizures</td>
</tr>
<tr>
<td>□ Fragile X</td>
<td>□ Tactile</td>
<td>□ Cardiac Condition</td>
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<tr>
<td>□ Intellectual disability</td>
<td>□ Proprioceptive</td>
<td>□ Obesity</td>
</tr>
<tr>
<td>□ Rett syndrome</td>
<td>□ Vestibular</td>
<td>□ OSA</td>
</tr>
<tr>
<td>□ Spina bifida</td>
<td>□</td>
<td>□ Other (Specify):</td>
</tr>
<tr>
<td>□ Tourette syndrome</td>
<td>□</td>
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<td>□ Other (Specify):</td>
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<table>
<thead>
<tr>
<th>Degenerative:</th>
<th>Co-occurring Psychological Issues:</th>
<th>Metabolism:</th>
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<td>□ Muscular dystrophy</td>
<td>□ Depression</td>
<td>□ Congenital hypothyroidism</td>
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<td>□ Other (Specify):</td>
<td>□ Aggression</td>
<td>□ Phenylketonuria</td>
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<td>□ Other (Specify):</td>
<td>□ Anxiety</td>
<td>□ Other (Specify):</td>
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<tr>
<td>□ Relational</td>
<td>□ Self-injurious behavior</td>
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<tr>
<td>□ Other (Specify):</td>
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<table>
<thead>
<tr>
<th>Etiology</th>
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<tbody>
<tr>
<td>□ Genetic/Chromosomal</td>
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<tr>
<td>□ Preterm Birth</td>
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### Adaptive Functioning Domains

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<th>Domain</th>
<th>Details</th>
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<tbody>
<tr>
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<tr>
<td>Social</td>
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<tr>
<td>Self Direction</td>
<td></td>
</tr>
<tr>
<td>Community Activities</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
</tr>
<tr>
<td>Functional Academics</td>
<td></td>
</tr>
<tr>
<td>Functional Grade Level</td>
<td>Date Tested:</td>
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<tr>
<td>FSIQ</td>
<td>Date Tested:</td>
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### Home Living:

<table>
<thead>
<tr>
<th>Details</th>
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### Leisure:

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<tr>
<th>Details</th>
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### Sleep Issues:

<table>
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### Nutritional Issues:

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### Quality of Life Issues:

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### Safety Issues:

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### Emergency Care Plan

<table>
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<tr>
<th>Details</th>
<th>Relationship</th>
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<tbody>
<tr>
<td>Emergency Contact</td>
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<tr>
<td>Preferred Emergency Care Location</td>
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</table>

### Common Emergent Presenting Problems

<table>
<thead>
<tr>
<th>Details</th>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
</tr>
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<tbody>
<tr>
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### Special Concerns for Disaster:

### Allergies and Procedures to be Avoided

<table>
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<tr>
<th>Details</th>
<th>Reactions</th>
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### Diagnoses and Current Problems

<table>
<thead>
<tr>
<th>Details</th>
<th>Details and Recommendations</th>
</tr>
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</table>

### Other

#### Adaptive Functioning Domains

- Communication
- Social
- Self Direction
- Community Activities
- Work
- Functional Academics
  - Functional Grade Level: Date Tested:
  - FSIQ: Date Tested:

#### Home Living

- Details

#### Leisure

- Details

#### Sleep Issues

- Details

#### Nutritional Issues

- Details

#### Quality of Life Issues

- Details

#### Safety Issues

- Details

#### Emergency Care Plan

- Emergency Contact: Relationship: Phone:
- Preferred Emergency Care Location:

#### Common Emergent Presenting Problems

<table>
<thead>
<tr>
<th>Details</th>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
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#### Special Concerns for Disaster:

#### Allergies and Procedures to be Avoided

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<th>Reactions</th>
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#### Diagnoses and Current Problems

<table>
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<th>Details and Recommendations</th>
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</table>
# Medical Summary & Emergency Care Plan for Young Adults with Intellectual/Developmental Disabilities

## Medications

<table>
<thead>
<tr>
<th>Medications</th>
<th>Dose</th>
<th>Frequency</th>
<th>Medications</th>
<th>Dose</th>
<th>Frequency</th>
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</table>

## Health Care Providers

<table>
<thead>
<tr>
<th>Health Care Provider</th>
<th>Name</th>
<th>Phone</th>
<th>Fax</th>
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</thead>
<tbody>
<tr>
<td>Primary Care Provider</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Specialty Provider</td>
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</tr>
<tr>
<td>Clinic or Hospital Provider(s)</td>
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<tr>
<td>Speech Therapist</td>
<td></td>
<td></td>
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<tr>
<td>Physical Therapist</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Occupational Therapist</td>
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<tr>
<td>Mental Health/Psychiatry</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Other</td>
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## Prior Surgeries, Procedures, and Hospitalizations

<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
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## Baseline

**Baseline Vital Signs:**

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<thead>
<tr>
<th>Ht.</th>
<th>Wt.</th>
<th>RR</th>
<th>HR</th>
<th>BP</th>
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</thead>
</table>

**Baseline Neurological Status:**

## Most Recent Labs and Radiology

<table>
<thead>
<tr>
<th>Test</th>
<th>Date</th>
<th>Result</th>
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<table>
<thead>
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<tr>
<td>EKG</td>
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<tr>
<td>X-Ray</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C-Spine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRI/CT</td>
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</table>

Other (Specify):
**Equipment, Appliances, and Assistive Technology**

<table>
<thead>
<tr>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrostomy</td>
</tr>
<tr>
<td>Adaptive Seating</td>
</tr>
<tr>
<td>Wheelchair</td>
</tr>
<tr>
<td>Tracheostomy</td>
</tr>
<tr>
<td>Communication Device</td>
</tr>
<tr>
<td>Orthotics</td>
</tr>
<tr>
<td>Suctions</td>
</tr>
<tr>
<td>Monitors:</td>
</tr>
<tr>
<td>Crutches</td>
</tr>
<tr>
<td>Nebulizer</td>
</tr>
<tr>
<td>Apnea</td>
</tr>
<tr>
<td>02</td>
</tr>
<tr>
<td>Walker</td>
</tr>
<tr>
<td>Suctions</td>
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<tr>
<td>Apnea</td>
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<tr>
<td>02</td>
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<tr>
<td>Walker</td>
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</table>

**Other (Specify):**

<table>
<thead>
<tr>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**School and Community Information**

<table>
<thead>
<tr>
<th>Agency/School</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
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<tr>
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<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient/Guardian Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Primary Care Provider Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Care Coordinator Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
This document should be completed by youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their readiness to transition to an adult health care provider. If a youth’s intellectual or developmental disabilities prevent him or her from independently filling out this document, the youth’s caregiver should fill out the caregiver version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what you already know about your health and using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date:  
Name: Date of Birth: 

### Legal Choices for Making Health Care Decisions

- [ ] I can make my own health care choices.
- [ ] I need some help with making health care choices (Name: ___________ Consent: ___________).
- [ ] I have a legal guardian (Name: ___________).
- [ ] I need a referral to community services for legal help with health care decisions and guardianship.

### Personal Care

- [ ] I care for my all my needs.
- [ ] I care for my own needs with help.
- [ ] I am unable to provide self-care, but can direct others.
- [ ] I require total personal care assistance.

### Transition and Self-Care Importance and Confidence

**On a scale of 0 to 10, please circle the number that best describes how you feel right now.**

<table>
<thead>
<tr>
<th></th>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
</tr>
</thead>
<tbody>
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<td>How important is it to you to take care of your own health care and change to adult doctor before age 22?</td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td>How confident do you feel about your ability to take care of your own health care and change to an adult doctor before age 22?</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

### My Health

**Please check the box that applies to you right now.**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes, I know this.</th>
<th>I need to learn.</th>
<th>Someone needs to do this... Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know my medical needs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can tell other people what my medical needs are.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what to do if I have a medical emergency.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know the medicines I take and what they are for, and when I need to take them without someone reminding me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what medicines I should not take.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what I am allergic to, including medicines.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can name 2-3 people who can help with my health goals.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can explain to people how my beliefs affect my care choices.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Using Health Care

**Please check the box that applies to you right now.**

<table>
<thead>
<tr>
<th>Statement</th>
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</thead>
<tbody>
<tr>
<td>I know or I can find my doctor’s phone number.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I make my own doctor appointments.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before a visit, I think about questions to ask.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a way to get to my doctor’s office.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know I should show up 15 minutes before the visit to check in.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know where to get care when my doctor’s office is closed.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Using Health Care

<table>
<thead>
<tr>
<th>Task</th>
<th>Yes, I know this.</th>
<th>I need to learn.</th>
<th>Someone needs to do this... Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a folder at home with my medical information, including my medical summary and emergency care plan.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have a copy of my plan of care.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to fill out medical forms.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know how to ask for a form to be seen by other doctors or therapist.</td>
<td>☐</td>
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<td>☐</td>
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<tr>
<td>I know where my pharmacy is and what to do when I run out of my medicines.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know where to get a blood test or x-rays if the doctor orders them.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I carry my health information with me every day (e.g. insurance card, allergies, medications, and emergency phone numbers).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I know that when I am 18 the rules about my health privacy change.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have a plan so I can keep my health insurance after 18 or older.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td><em>(If applies) I have a plan so I can keep my disability benefits (SSI) after 18.</em></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities

This document should be completed by caregivers of youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their youth’s readiness to transition to an adult healthcare provider. If a youth’s intellectual or developmental disabilities do not prevent him or her from independently filling out this document, the youth should fill out the youth version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what your youth already knows about their health and using healthcare and areas that you think they/you need to learn more about. If you need help completing this form, please let us know.

<table>
<thead>
<tr>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Name:</td>
</tr>
<tr>
<td>Date of Birth:</td>
</tr>
<tr>
<td>Caregiver Name:</td>
</tr>
<tr>
<td>Are you the main/full-time caregiver? □ Yes □ No</td>
</tr>
</tbody>
</table>

### Decision-making/Guardianship
- □ My youth can make my own health care choices.
- □ My youth needs some help with making health care choices (Name: __________ Consent: __________).
- □ My youth has a legal guardian (Name: __________).
- □ My youth/I need a referral to community services for legal help with health care decisions and guardianship.

### Personal Care
- □ My youth can care for all his/her needs.
- □ My youth can care for his/her own needs with help.
- □ My youth is unable to care for himself/herself, but can tell others his/her needs.
- □ My youth requires help for all his/her needs.

### Transition Importance and Confidence

On a scale of 0 to 10, please circle the number that best describes how you feel right now.

<table>
<thead>
<tr>
<th>How important is for your youth to prepare for and change to an adult doctor before age 22?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How confident do you feel about your youth’s ability to prepare for and change to an adult doctor before 22?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not)</td>
</tr>
</tbody>
</table>

### Your Youth’s Health

Please check the box that applies to you right now.

<table>
<thead>
<tr>
<th>Your youth knows his/her medical needs.</th>
<th>□</th>
<th>□</th>
<th>□</th>
</tr>
</thead>
<tbody>
<tr>
<td>My youth can tell other people what his/her medical needs are.</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My youth knows what to do if he/she has a medical emergency.</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My youth knows the medicines he/she takes and what they are for.</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My youth can take his/her medicine by himself/herself without a reminder.</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>My youth knows what medicines he/she should not take.</td>
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<tr>
<td>My youth can name 2-3 people who can help him/her with his/her health goals</td>
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<td>□</td>
<td>□</td>
</tr>
<tr>
<td>My teen can explain to people how his/her beliefs affect his/her care choices.</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
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</table>
## Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities

### Using Health Care

<table>
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<tr>
<th>Task</th>
<th>Yes, my youth knows this</th>
<th>My youth needs to learn this</th>
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<td>Before a visit, my youth thinks about questions to ask.</td>
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<td>My youth knows he/she should show up 15 minutes before the visit to check in.</td>
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<td>My youth knows where to get care when his/her doctor’s office is closed.</td>
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<td>My youth has a folder at home with his/her medical information, including his/her medical summary and emergency care plan.</td>
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<td>My youth carries health information with him/her every day (e.g. insurance card, allergies, medications, and emergency phone numbers).</td>
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<td>☐</td>
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<td>My youth knows when he/she is 18 the rules about his/her health privacy change.</td>
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The “Medical ID” Feature on Apple’s Health app

For most people -- especially young adults -- a smartphone is everything. It’s a way to talk, text, take photos, play games, listen to music, read the news, and more. Now, the new iPhone Health app features a helpful medical tool: **the Medical ID.** The Medical ID shows important health-related information from the user. It is easy to set up and can be accessed by anyone in the event of an emergency. (NOTE: the “Medical ID” feature is only available on iPhones that have been updated to iOS 8. All photos are from Guiding Tech [http://www.guidingtech.com/33678/iphone-medical-id/].)

### Setting Up Your Medical ID

1. Open the Health app on your iPhone. At the bottom of the screen, tap the bottom right where it says *Medical ID* to get started.

2. On the next screen, you will be asked to create your own Medical ID. Once you do so, you will see the *Show When Locked* option. This will let anyone access your Medical ID even if your phone is locked and password-protected. This is important to do, so that your info can be viewed in case of an emergency.

Check out [www.GotTransition.org](http://www.GotTransition.org) for health care transition tools and resources
3. Add your relevant health information into the app. You can add your name, photo, and all the information you would want others to know about your medical condition. This includes allergic reactions, medications, blood type, and if you are an organ donor. You can even add an emergency contact with his/her name and relation to you.

4. Once you finish this step, tap Done at the top right of the screen. Your Medical ID is ready to use!
Accessing a Medical ID from a Locked iPhone

To access the Medical ID, first try to unlock the iPhone. This will bring up either the passcode or password screen (both shown below).

In either case, there is an *Emergency* button on display. Tap it to be taken to the ‘Emergency Call’ screen.
There, at the bottom left you will see the Medical ID button. Tap on it to reveal the user’s Medical ID.
Putting the Medical ID feature on Android Phones

Android phones usually don’t have built in health apps that allow you to create a Medical ID. But people with Android phones can still create Medical IDs that anyone can see from the lock screen without unlocking the phone. There are apps you can download that can give you a Medical ID. You can look on your own for one that you like. The rest of this guide will show you how to make a Medical ID using the free app Medical ID (Free) ICE Contacts.

1. First, you need to download the app. Go to the app store and download Medical ID (Free) ICE Contacts.

2. Open the new app, and you can create a profile. Fill out the profile with as much as you want, which includes: first name, last name, gender, birthday, blood type, height, weight, organ donor, medical conditions, allergies & reactions, medications, and medical notes.

3. Then, tap the check mark in the upper right corner to finish the profile. Your Medical ID is ready!

Check out www.GotTransition.org for health care transition tools and resources
You’ll see a screen with all the profiles, like this one. Tap on the three dots upper right to change any settings.

This is the settings menu. Tap on *Lock Screen* to see the different options for Medical ID.

You can try them all and see which you like best. Lock your phone to see what they look like.
Here is what the “Floating icon” looks like when the phone is locked:

To see your Medical ID, tap twice on the red icon at the top.

This is what your Medical ID will look like:
Transition Policy:

The Goldberg Center is committed to helping all of our patients make a smooth transition from pediatric to adult care. This process requires working with you to plan and prepare your transition starting around your 14th birthday. According to hospital policy, all patients are expected to transition from Children’s National to an adult primary care medical home by 22 years. We will provide you with ongoing resources to help you to take increasing responsibility for your own healthcare to the best of your abilities. We are also able to help you select a medical provider that participates with your insurance, to organize your medical records, and to support all other aspects of planning for this important transition as part of lifelong preparation for a successful and well adult life.
<table>
<thead>
<tr>
<th>Last Name</th>
<th>First Name</th>
<th>Middle Name</th>
<th>Patient Account Number</th>
<th>Assigned PN</th>
<th>RA Completion Status</th>
<th>Patient DOB</th>
<th>Age as of Today</th>
<th>Guardian Name</th>
<th>Relationship</th>
<th>Patient Language</th>
<th>Primary Service Location</th>
<th>Primary Insurance Name</th>
<th>Primary Diagnosis</th>
<th>First Attempt Date</th>
<th>Projected Second Attempt Date</th>
<th>Actual Second Attempt Date</th>
<th>Projected Third Attempt Date</th>
<th>Actual Third Attempt Date</th>
<th>RA Admin. Date</th>
<th>Feedback</th>
</tr>
</thead>
</table>
Transition Readiness Assessment for Parent/Caregiver and Youth/Young Adult

Navigator will fill out this form to identify if the youth or young adult is aware of their health needs, how to access services and identify goals for them to learn more about.

<table>
<thead>
<tr>
<th>Date:</th>
<th>Form Completed by:</th>
<th>☐ Youth/Young Adult</th>
<th>☐ Parent/Caregiver</th>
<th>☐ Legal Guardian</th>
</tr>
</thead>
</table>

**Name:**

**Date of Birth:**

**Transition and Self-Care Importance and Confidence**

*On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

**How important is it for the young adult to manage their own health care?**

<table>
<thead>
<tr>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
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</table>

**How confident do youth feel about their ability to manage their own health care?**

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<th>3</th>
<th>4</th>
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<th>10 (very)</th>
</tr>
</thead>
</table>

### My Health

**Please check the box that applies to you right now.**

**Yes, I know this** | **I need to learn** | **Someone needs to do this…Who?** | **Does not apply**

1. Knows their own diagnoses
2. Knows how to explain their diagnosis
3. Knows their own medical needs
4. Knows how to explain their medical needs
5. Knows their symptoms including ones that they quickly need to see a doctor for
6. Knows what to do in case of a medical emergency
7. Knows their own medicines, and why their taking them
8. Knows their allergies to medicines and the medicines they should not take
9. Knows what to do in the event of an allergic reaction
10. Knows their assistive devices and medical equipment needs
11. Knows the name/person of who can help with their health goals
12. Knows how to explain to others how their customs & beliefs affect their health care decisions

### Using Health Care

13. Knows their doctor/providers and how often to see them
14. Knows how to contact their doctor
15. Knows how to make their own doctor appointments
16. Knows to think about questions to ask the doctor before their visit
17. Knows how to get to their doctor’s office
18. Knows where to go to get medical care when the doctor’s office is closed
19. Knows to carry important health information with them every day (e.g. insurance card, medications, emergency contact information, medical summary).
20. Knows to have a file at home for their medical information
21. Knows how to fill out medical forms
22. Knows how to get referrals for other health care providers
23. Knows how to order medical supplies
24. Knows where to get blood work or x-rays done if the doctor orders them
25. Knows where the pharmacy is and how to refill their medicines
26. Knows how health care privacy changes at age 18 when legally an adult
27. Knows how to discuss with family about how to make their own health care decisions at age 18
28. Knows what to do to keep their insurance after 18 or older

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Parent Navigator - (17000218)

Description
Provide direct patient service by linking families to resources at Children’s and in the community. Interact with patients, parents and other family members, physicians and other staff under moderate supervision in a courteous manner. Maintain referral data base and assists in generating monthly reports.

Provide direct patient service by linking families to resources at Children’s and in the community. Interact with patients, ervision in a courteous manner. Maintain referral data base and assists in and assisting in generating monthly reports

Qualifications

Minimum Education
High School Diploma or GED

Minimum Work Experience
2 Year(s)

Specific Requirements and Preferences
At least 2 years of related experience. May include experience as employee in a medical setting or as a patient or family member in the health care system. Experience as parents or guardians of children with special health care needs preferred.

Required Skills/Knowledge

Strong organizational and customer service skills required. Computer knowledge including Microsoft Word and Excel necessary. Familiarity with Children’s National Health System and community resources for children with special health care needs preferred. Spanish language skills may be required at designated health centers.

Communications

1. Use range of communication skills to assist patient’s needs and staff requests.
2. Communicate with relevant hospital staff about patient care.
3. Participate in staff meetings and quality improvement activities to address patient care issues.
Patient Support

1. Help patients schedule specialist appointments and verify appointments.
2. Advocate for patient needs within the hospital system.
3. Assist with referral process as needed.
4. Follow-up with families to ensure needs met.

Safety

1. Speak up when team members appear to exhibit unsafe behavior or performance
2. Continuously validate and verify information needed for decision making or documentation
3. Stop in the face of uncertainty and takes time to resolve the situation
4. Demonstrate accurate, clear and timely verbal and written communication
5. Actively promote safety for patients, families, visitors and co-workers
6. Attend carefully to important details - practicing Stop, Think, Act and Review in order to self-check behavior and performance

Organizational Accountabilities (Staff)

Office Work

1. Receive and log in referrals to Family Liaison.
2. Assist in generation of monthly and annual reports.
3. Document all referrals in the data base and track outcomes.

Organizational Commitment/Identification

1. Partner in the mission and upholds the core principles of the organization
2. Committed to diversity and recognizes value of cultural ethnic differences
3. Demonstrate personal and professional integrity
4. Maintain confidentiality at all times

Customer Service

1. Anticipate and responds to customer needs; follows up until needs are met
Teamwork/Communication

1. Demonstrate collaborative and respectful behavior
2. Partner with all team members to achieve goals
3. Receptive to others’ ideas and opinions

Performance Improvement/Problem-solving

1. Contribute to a positive work environment
2. Demonstrate flexibility and willingness to change
3. Identify opportunities to improve clinical and administrative processes
4. Make appropriate decisions, using sound judgment

Cost Management/Financial Responsibility

1. Use resources efficiently
2. Search for less costly ways of doing things

Primary Location
: District of Columbia-Washington

Work Locations
:
Sheikh Zayed Campus
111 Michigan Avenue
Washington 20010

Job
: Non-Clinical Professional

Organization
: Goldberg Cntr Cmnty Ped Hlth

Regular / Temporary: R (Regular)
Position Status: FT - Full-Time
Shift: Day
Work Schedule: M-F
Job Posting
: Jan 29, 2018, 2:39:02 PM